

Impact of a Cochlear Implant on A Teenager's Quality of Life: A Parent's Perspective

By CONNIE BOUSE

Scott Bouse is a 14-year-old boy with a profound, bilateral sensorineural hearing loss. He received a Nucleus 22 Channel Cochlear Implant when the hearing loss in his left ear had progressed to the point at which he could no longer benefit from a hearing aid on that ear, and at the same time his aided right ear provided only minimal functional hearing. Today Scott wears both devices, integrating the two sources of information, and deriving benefit from both. Although improvement in auditory perceptual tests is not as dramatic as we had expected, the change in Scott is.

His mother, Connie, began to keep a diary on the first day Scott received the external components of the cochlear implant. The article that follows is an outgrowth of her diary, which relates Scott's experiences before the cochlear implant and immediately after receiving it, and tells how he is functioning a year later.

Scott grew up in Sheridan, a small rural town in north-central Indiana, with his parents, Connie and Chuck, and younger sister, Stacey, all of whom have normal hearing. His friends live nearby; however, Scott had to ride the bus to school 15 miles away to participate in a program for hearing-impaired children. He had few friends at the new school and felt isolated when mainstreamed to regular classrooms.

As Scott's speech-language therapist, it has been exciting watching him "break out of his cocoon," following the cochlear implant. He has started to display more self-confidence, to enjoy school and sports activities, and to make more friends. His mother describes this process in her own words, leading up to the fulfillment of her dream of seeing Scott attend school in his own community.

—Marjorie Kienle, MEd
Speech-Language Pathologist
Methodist Hospital of Indiana

Last April, my 14-year-old son Scott heard birds singing for the first time. The expression on his face said it all—he was overwhelmed. At first, he could hear it, but he couldn't determine its source, so he went outside in search of the sound that had brought wonder to his face.

Scott was born on March 25, 1973 with a permanent hearing impairment. At age two, he was fitted with hearing aids in both ears. He learned to speak and lip-read at various clinics and has had speech therapy. He also has had teachers for

the hearing impaired, although he has been mainstreamed into neighborhood schools.

Scott's speech has always been hard to understand, which has had tremendous effects on his personality. With strangers, he was backward and shy. His fear of having to speak made him avoid new people. He never went anywhere by himself, would not go shopping, and never made conversation with any of the adults in the neighborhood because he was afraid they wouldn't understand him, and he didn't always understand what they said.

I practically had to force him to join sports teams at school. The only place he seemed to feel comfortable enough to express himself was in his class for the hearing impaired. There, he became the class clown.

At home, Scott's efforts to communicate made him loud and somewhat rowdy in behavior. To get his attention, the family had to yell, or we had to walk up and tap him on the shoulder. Ironically, his hearing impairment made for a noisy household, and it was frustrating for all of us—but especially for Scott. Frustrated at being unable to communicate, he responded frequently with temper tantrums.

Stacey, Scott's younger (by two years) sister became his "ears." Even when my husband Chuck or I couldn't understand him, Stacey usually managed. As a result, I think they developed a very close relationship. That's not to say they never squabble, or aren't sometimes envious of each other, but they have always had a special bond.

PROSPECT OF A COCHLEAR IMPLANT

When Scott was in fourth grade, his teacher noticed that he was not doing as well as he had been. In December of that year, 1982, we consulted Dr. Jerry House of Methodist Hospital of Indiana, who tested Scott and discovered he had lost almost all hearing (95%) in his left ear and 70% in his right. We do not know what had caused the loss. What was certain was that Scott's condition would be permanent.

In July 1985, Dr. House's office called. He and audiologist Jon Shallop, PhD wanted us to bring Scott in for testing. They were studying a device called the Nucleus 22 Channel cochlear implant to see if it could help adolescents with hearing impairments.

The doctors explained that these were merely listening tests and none were dangerous. At that time, they warned us that even if Scott were a candidate, the procedure might not be available for three to five years.

As miracles would have it, Dr. House called us in January 1986 to tell us that the Food and Drug Administration (FDA) had authorized testing the device on deafened adolescents 10 to 17 years old, and he told us how the implant could help Scott. He said that the cochlear implant was designed to help people with profound hearing loss as a result of diseases of the inner ear that cause nerve deafness. Because of this, the implant would let Scott, who could not discriminate words using a hearing aid, hear sounds and words again.

If Scott responded like most recipients, we were told, he would have restored sensation of sound, increased ability to recognize conventional speech with lipreading, and awareness of normal everyday sounds such as doorbells, car motors, background music (and singing birds!). There would also be the possibility of his recognizing speech without lipreading—for instance, he might be able to carry on a two-way conversation over the telephone.

Before the implant, Scott would first have to undergo a series of tests, the doctors said. Some would be slightly uncomfortable. (Scott later said he felt only "a pinch" during one test.)

FEAR OF SURGERY

Scott would be the first teenager to have the operation. His father and I had a lot of sleepless nights wondering whether it was the right thing to do—and not knowing for sure if it would work. Scott, who had never been to the hospital before, was frightened by the idea of surgery, afraid that he might wake up during the operation, afraid of seeing blood. He was also afraid he wouldn't wake up at all. Scott's reluctance came not so much from the idea of the implant itself, but from everything surrounding the operation for it. After all, he could be expected to understand only so much of the intricacies of the cochlear implant and how it worked, but what struck him most was a fear of the unknown. He just didn't know what to expect or if it would help him. And, not surprising for a 13-year-old was his objection to having his head shaved and then having to go to

school and contend with the kids. That upset him terribly.

Despite his fears and our own—none of which were realized—we decided to go for it. Chuck and I normally let our kids make their own decisions, but this was just too big. We had to convince Scott. It was a chance we had to take.

On the morning of the operation, February 27, 1986, Scott was very nervous. The surgery itself took a little over three hours—the longest three hours of my life. When they took him up to his room, Scott was very sleepy and had some pain. He said his head felt like a balloon, with all the bandages they put on him. He came home the next day and, although he had a slight headache and dizziness for the next few days, he made a quick recovery.

IMMEDIATE POST-OP

By March 7, eight days later, Scott was able to have the stitches taken out. His hair was already starting to grow back. He worried whether the slight lump from the implant would ever go away.

He was uncomfortable for about 14 days following surgery, but he was starting to feel like himself almost immediately. Before he started back to school, he and I visited his old grade school. Surprisingly, he wasn't self-conscious. He talked with the younger kids about his operation and seemed at ease.

Several days later Scott went back to junior high school. He feared ridicule about his scar and his very short haircut, but after we were there for a short while, the other kids began asking questions and he began to relax. It didn't hurt that they had put up a big sign on the bulletin board welcoming him back. Things went smoothly through March and, in

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April, it was time for what they call "the hookup." By that time, his hair had grown back completely and the slight lump from the implant was not even noticeable. Scott had fun with the idea that he would have a "bionic ear."

The day of the hookup was a very emotional one for all of us. We would finally know if it was going to work. After Dr. Shallop connected and set the processor, he let Chuck say "Hi" to his son. Scott was the first to cry, but we all did. We were all so happy. The following week we started intensive therapy with Marjorie Kienle, Scott's cochlear implant speech therapist.

Scott went to school the day after the hookup with his headband and his processor. Much to our surprise, he thought it was "neat." It took a few days to get everything set so that Scott was happy with the adjustment of his processor. He was expending tremendous energy on listening and on getting used to the new device and new sounds. There were many days that he would come home from school very, very tired. But,

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The Bouse family (l-r): Connie, Chuck, and Scott.

for Scott, the discovery of sound was like getting a glorious new wardrobe after living in a single suit of clothing.

He has received therapy at school, where he is assisted by two Honor students—a boy and a girl who come in 20 minutes each day to do speech tracking with him. It has taken months of therapy and very hard work, but Scott's speech has changed a great deal. Neighbors, family, friends, classmates, and teachers can understand him better. Now, I can tell immediately by the quality of Scott's speech whether he has the implant turned on or off. If it is on, his speech is very clear; if it is off, his speech is very sloppy.

At first, everything was too loud to him, particularly the school cafeteria. He said water sounded funny and that all women sounded just like me. Once the adjustments were made, things became measurably better.

He'd sit in the living room or in the car or wherever and hum to himself, because it was the first time he had really heard his own voice. And he loved the sound of it. He just kept listening and listening. He'd say, "Mom, do you hear me, do you hear me?" It was great. He spent hours



April 1986: Scott's first "hookup."

listening to his grandmother's cat purring. He can hear doorbells now, and he can talk on the telephone.

SCOTT TODAY

Scott is much quieter since the operation, because now he can hear himself. We no longer have to yell at him to get his attention. Now he usually responds to my voice the first time I say something to him; if not, definitely by the second time.

But, I think the most important thing that has happened to Scott is that he has more self-confidence. When we were at the ballpark last summer, he refused to go to the concession stand by himself. This year, we find he's a different person. At a recent ball game, his dad asked him to go get a hot dog and a Coke and gave him the money, and Scott went and did it, without his usual apprehension. We were shocked—and delighted.

When he asked me recently if he could go to the grocery store, I was floored. He even enjoys going shopping now. He is listening to the radio and picking up certain songs, and loves to go to sock hops at school. He has even discovered girls. No one would ever know that he couldn't hear or had an implant now, and the kids treat him just like everyone else. He is talking much more now too—even to the neighborhood adults. And to my surprise, they can understand most of what he is saying. Before, they were never sure and, I think, were afraid to admit it.

Scott recently was invited to attend a convention for the Indiana Association for the Hearing Impaired to present a plaque to Jeff Float, the Olympic swimmer. Needless to say, it was quite exciting for us all. As Scott was about to shake Jeff's hand, Jeff said, "Please, Scott, read the plaque to everyone." There were about 60 people there. It really took Scott by surprise. Nevertheless, he read the plaque, word for word, in a voice and

speech that everyone could understand. We were all so proud of him. It was his first time at anything like this. What a thrilling experience to see Scott accomplish that feat after all his hard work.

Each of us who knows and is close to Scott has a favorite example of the change in him. His school bus driver couldn't believe the difference in his speech. She related to us that, at Christmas time, she had the radio on in the bus and Scott asked her to turn it up so that he could hear "Jingle Bells."

Over the holidays, we visited with family members who had not seen Scott since the implant. They noticed the difference immediately, remarking that he was a lot quieter and that his speech was better. It was the first time many of Scott's relatives could understand and communicate with him.

My husband teases that we have made a monster out of him, because now he wants to go and do so many things that he never would before; but this has changed all our lives for the better. I think it is great because I no longer have to talk for him, nor take him everywhere, as I used to. Now, he does things on his own. I have seen my son grow from a little boy into an average teen in just a few short months, all because of the implant.

This implant has done more than we ever expected it to. My own hope for the operation was that it would enable Scott to regain the hearing he had lost in his left ear. It has done that and much, much more. It has brought him out of his shell. That aspect by itself is fantastic. The implant has had an enormous impact on the quality of his life.

We still have a long road ahead of us. Scott's current therapy consists of listening to words and speech to familiarize himself with the sounds. The more he works with the implant, the better his speech and hearing will get. It is significant that Scott is now picking up some speech without lipreading.

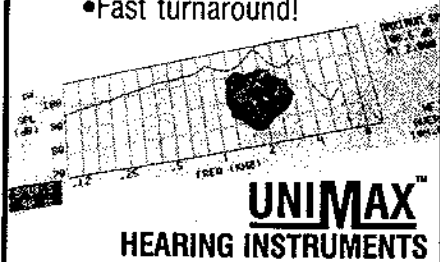
Scott now is doing fine in school. His teacher tells me he is picking up on things in class a lot more quickly and is responding better, and both his teacher and his therapist are very pleased with his progress. We all are.

RECOMMENDATIONS TO PROFESSIONALS

If anyone were to ask me now whether we would "do it over again," I would say a resounding, "yes." For any parent that has a hearing-impaired child who would be helped by a cochlear implant, I would say, "Do it. Don't wait." The earlier an impaired person can get the implant and the more he can work with it, the better it will be for the rest of his life. This is especially true of young people, who are in

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Scott at school, October 1986.

The Nucleus 22 Channel Cochlear Implant

The internal components of the Nucleus 22 Channel system comprise a tiny audio receiver that is implanted surgically in the bone behind a patient's ear, and a special electrode array with 22 separate channels that is surgically inserted in the inner ear. After about four to six weeks of healing time, a patient is fitted with the system's external parts: a microphone and a transmitter on a lightweight headband, connected by wires to a speech processor (a miniature computer), which the patient wears in a shoulder pouch, a pocket, or on a belt.

The microphone picks up sounds and relays them to the speech processor, which is custom-tuned by an audiologist to transmit those sounds that will help the individual patient interpret speech. The sounds are sent from the speech processor to the external transmitter. The transmitter then sends the sound impulses across the skin to the implanted receiver, and then on to the inner ear. There, the electrodes substitute for damaged sensory cells by directly stimulating the auditory nerve, which relays the signals to the brain where they are interpreted.

—Marjorie Kienle

the process of building their confidence and learning skills to interact socially. Scott is proof of that.

I would make several recommendations to the professionals who deal with hearing-impaired persons, and with cochlear implant recipients in particular.

- If a child or teen has never been through an operation, don't hesitate to reassure him that he will wake up when it's over. Be aware of what the child's specific fears are and discuss them with the child. Examine the fear realistically and never try to shame the child out of it or ridicule the child's feelings.
- If possible, familiarize the child or adolescent in advance with the hospital surroundings. (We were fortunate in that the hospital where Scott was to have the implant surgery provided a preadmission tour of the patient floors and the recovery and operation rooms. The staff explained in advance where Scott would be at all times and what procedures would be performed in each locale. It really helped to relieve his mind. Familiarity made the situation easier on him. He was still scared about the operation, but the tour took the edge off that fear.)
- Upon admission for surgery, hospitals should make sure a young patient doesn't have to wait for forms to be filled out, blood to be drawn, or other tests to be performed before getting settled in his or her room. The delay in getting settled tends to make the fear worse.
- Have parents involve teachers of the hearing impaired, to help them to understand the implant procedure and the therapy the child is receiving,

as well as the underlying hearing problem the child suffers. Parents must assist in this by being candid with the teacher and willing to answer any questions the teacher might have. They should give the teacher a brief explanation of the procedure and show where the device is located and how it works.

- It is crucial to the parents' ability to communicate with teachers and others that professionals talk to parents on a level they understand, and avoid talking "over their heads."
- Parents and teachers must recognize that the implant will take some adjustment for the child, along with hard work in therapy. Counsel parents to be aware of changes in the child as a result of his or her new hearing, and expect that there will be readjust-

ments for the families as the child becomes more independent and outgoing.

- For the most part, common sense and an understanding of children are what are required for dealing with young implant users.

The rewards of seeing a child blossom when exposed to sound and enriched by the gift of speech are enormous. It still gives me shivers to think that something Chuck and I have done for our son has transformed his life and brought him to the point where he can live normally in a hearing world. Scott's teenage recollections will be different from those of other boys. No doubt, his first date and getting his driver's license will be second and third on his list.

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